Dear Friends of HDSA,

After navigating through another year of COVID-19 and moving more events to virtual platforms, HDSA continued pushing forward to improve the lives of families impacted by Huntington’s disease. On top of all the challenges of a pandemic, we received disappointing research news earlier in the year. With all the challenges we faced, the HD community remained relentless in our fight against HD and we cannot thank our donors and loyal corporate partners enough for their amazing support.

In early 2021, we expanded HDSA’s Centers of Excellence program to a record 54 HD care teams with eight satellite sites across the country. We funded five research grants under the Society’s largest research initiative, the HDSA Huntington’s Disease Human Biology Project. We also awarded two Berman-Topper Family HD Career Development Fellowships, and two Donald A. King Summer Research Fellowships, a vital program to train the next generation of scientists with research expertise in Huntington’s disease.

For a full breakdown of HD research from this past year, I encourage you to read The Marker: HDSA’s 2021 Research Report which can be found at HDSA.org/marker21.

For the second consecutive year, the Annual HDSA Convention was moved to a virtual event where we welcomed thousands from across the globe. Thanks to the commitment of our speakers, exhibitors and sponsors, as well as the dedicated volunteers who once again ensured that the extraordinary magic of HDSA Conventions was preserved.

Our extraordinary volunteers stepped up in the face of adversity to coordinate creative events that allowed folks to participate in HDSA’s mission work in many ways. A prime example is the virtual Seventh Annual Freeze HD event held in October that raised more than $212,000 and generated an enormous amount of awareness thanks to the amazing work of the Freeze HD Committee.

Aside from the events and fundraising initiatives, the power of storytelling helped HDSA generate more than two billion media impressions — the most ever! During a very ‘loud’ media year filled with political and health headlines, this meant that HDSA news and Huntington’s disease stories reached more people than ever before to educate and motivate them in our work. The fight to continue to raise much-needed awareness continues to be an integral part in educating the world about HD.

One such major news story occurred in July when Kala Booth testified in front of Congress to encourage the passage of the HD Parity Act. With our most comprehensive push yet to move this crucial bill forward, HDSA volunteers from across the country have come together to contact their local representatives and build momentum for this important bill. From educational and fundraising events to advocacy and awareness, HDSA is able to provide help for today, hope for tomorrow for families affected by HD because of you.

Your relentless commitment is ensuring help and hope, until we finally live in a world free of HD. Thank you for your continued support!

With hope,

Louise Vetter
President & Chief Executive Officer
HDSA Centers of Excellence

HDSA Expands Centers of Excellence Network to 54 Clinics and Adds Eight Partner Sites

In February, HDSA announced that fifty-four outstanding Huntington’s disease care facilities were awarded the designation of HDSA Centers of Excellence. In 2021, HDSA awarded $1,750,000 to the Centers of Excellence network.

The HDSA Centers of Excellence are multi-disciplinary care teams with expertise in Huntington’s disease that share an exemplary commitment to providing comprehensive care. The strategic expansion of the HDSA Centers of Excellence network allows expanded access to expert HD clinical care and clinical trial opportunities to more families across the United States. With new Centers in Arizona, Arkansas, New Jersey, Mississippi, Ohio and South Carolina, HDSA now offers care locations in 35 States plus the District of Columbia.

“The expansion of the HDSA Centers of Excellence program ensures that more families affected by Huntington’s disease have increased access to expert and comprehensive care for this devastating rare brain disease,” said Dr. Victor Sung, Chair of HDSA’s National Board of Trustees and Director of the HDSA Center of Excellence at The University of Alabama, Birmingham. “Additionally, clinical research conducted at many HDSA Centers of Excellence is vital to the development of potentially life-changing treatments to improve the lives of everyone affected by Huntington’s disease.”

Learn more about HDSA’s Centers of Excellence network, by visiting HDSA.org/coe.

HDSA Centers of Excellence Clinical Research Pilot Program

HDSA awarded two grants under the HDSA Centers of Excellence Clinical Research Pilot Program. These grants, totaling $25,000, represent HDSA’s patient-centric research focus by fostering novel clinical research projects within the HDSA Centers of Excellence network. These pilot projects will unite scientists with HD families through their direct participation in clinical research.

Two clinical research pilot grants were awarded this year.

Deb Kegelmeyer, DPT, at The Ohio State University. This study will evaluate whether telehealth is an effective medium to implement a 12-week movement to music program designed to enhance physical, cognitive, and psychosocial health in adults, as well as whether the intervention leads to changes in these domains.

Leonard Sokol, MD, at Northwestern University, for a study on Meaning-Centered Psychotherapy for treatment of psychosocial symptoms and improved quality of life in persons with Huntington’s disease.
In October of 2021, HDSA awarded five research grants under the Society’s largest research initiative, the HDSA Huntington’s Disease Human Biology Project. Totaling more than $728,000, these grants represent HDSA’s patient-centric research focus which brings basic and clinical researchers together to facilitate Huntington’s disease science in the human condition, instead of animal models, with direct participation of people affected by HD. HDSA received impressive applications from researchers all around the world. After careful consideration by HDSA’s Scientific Advisory Board, funds were ultimately granted to researchers from the United States, Canada, and Spain.

**2021 Human Biology Project Fellowships**

- **Ana Gámez-Valero, PhD**  
  Postdoctoral Research Scientist  
  University of Barcelona  
  Plasma extracellular small RNAs as early biomarkers of HD and indicators of dynamic changes in disease progression

- **Tamara Maluri, PhD**  
  Research Associate  
  McMaster University  
  Poly ADP-ribose dysregulation in HD patient samples and potential for therapeutic intervention

- **Joan O’Keefe, PhD, PT**  
  Associate Professor  
  Rush University  
  Neural underpinnings of cognitive, balance, and gait deficits in HD

**2021 Donald A. King Summer Research Fellowships**

With the goal of attracting the next generation of bright young scientists to HD research and preparing them for the challenges of the field, HDSA established the Donald A. King Summer Research Fellowship in 2005 to support undergraduate researchers in their study of biological mechanisms underlying HD pathology. This program was established to honor Donald A. King, a tireless advocate for HD families who served as HDSA’s Chairman of the Board from 1999 to 2003 before his sudden passing in 2004.

**2021 Berman-Topper Family HD Career Development Fellowships**

With a shared goal of bolstering opportunities for young HD researchers and generous support from the Berman and Topper families, HDSA launched the Berman-Topper HD Career Development Fellowship in 2016 to support future generations of passionate HD scientists and clinicians. These prestigious fellowships provide $80,000 of annual funding for three years to young scientists and clinicians who are motivated to make HD a focal point of their long-term career plans. Since its inception in 2016, the program has supported seven emerging scientists in projects that have not only propelled them forward in their careers, but also made significant contributions to the HD research community. This year, after HDSA’s Scientific Advisory Board carefully considered proposals from scientists across the globe, the Society was excited to name two 2021 Berman-Topper Fellows, Dr. Eduardo Silva-Ramos and Dr. Adys Mendizabal.
2021 HDSA Highlights

Dr. Jeff Carroll & Dr. Beth Hoffman Join HDSA's National Board of Trustees

“On behalf of HDSA’s Board of Trustees, we are excited to welcome Dr. Carroll and Dr. Hoffman” said HDSA’s President and CEO Louise Vetter. “They are both established scientific and volunteer leaders in the HD community whose experience will undoubtedly strengthen HDSA’s mission work.”

For more information about HDSA’s National Board of Trustees, please visit www.HDSA.org/bot

HDSA Partners With PatientsLikeMe®

The world’s largest integrated community, health management, and real-world data platform PatientsLikeMe (PLM) announced in June 2021 that it partnered with the Huntington’s Disease Society of America to launch a virtual community for those living with Huntington’s disease and for those caring for individuals living with HD. This tailored community will focus on education and peer-to-peer knowledge-sharing. This community will serve as a catalyst to expand researchers’ knowledge of the condition through the analysis of patient-generated data.

“Partnering with PatientsLikeMe is an exciting new step in our work to help families affected by Huntington’s disease come together to support one another, find vital resources and share their journeys so that care for HD improves as quickly as possible,” said Louise Vetter, President and CEO of the Huntington’s Disease Society of America.

To access the platform, visit HDSA.org/PLM

31 Days, 31 Stories

Sharing personal experiences is crucial in educating people about the impact HD has on individuals and families.

Videos featuring members of the HD community sharing their narratives have been posted on HDSA’s YouTube channel in HDSA’s 31 Days, 31 Stories series.

HDSA Reintroduces HD Parity Act

In March 2021, the Huntington’s Disease Society of America announced that Senators Kirsten Gillibrand (D-NY) and Dr. Bill Cassidy (R-LA), along with Representatives Adam Kinzinger (R-IL) and Bill Pascrell, Jr (D-NJ) have reintroduced the Huntington’s Disease Parity Act (S 868 / HR 2050). The HD Parity Act will waive the two-year Medicare waiting period, as well as waive the 5-month benefit waiting period for individuals with Huntington's disease (HD) accessing Social Security Disability Insurance (SSDI).

To learn more please visit HDSA.org/takeaction.

Kala Booth Testifies in Front of Congress

The Huntington’s Disease Society of America applauded the House Energy and Commerce Subcommittee on Health for holding a vitally important hearing on July 29th that put a spotlight Huntington’s disease. Kala Booth, an HD patient and caregiver, testified to the distinct challenges of living with HD, its multi-generational impact, and the importance of improving access to vital health benefits as outlined in the bipartisan Huntington’s Disease Parity Act.

May Is HD Awareness Month — #LetsTalkAboutHD

May Is HD Awareness Month, so #LetsTalkAboutHD! HDSA teamed up with members of the HD community to turn up the global volume to let the world know about this devastating brain disorder.

PASS THE HD PARITY ACT

On July 29th, the House Energy and Commerce Subcommittee on Health heard the testimony given remotely by HD patient and caregiver, Kala Booth (above) on the importance of the HD Parity Act.

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HDSA Films
In 2021, HDSA produced four inspiring films featuring HD families. Watch them today on HDSA’s YouTube Channel.
- The Dohertys: Finding the Funny
- The Osborns: Our Legacy
- The Osborns: My Father, My Hero

Ginny & Georgia Reunion
With help from HDSA’s dear friend Scott Porter, the castmates and creators of the hit Netflix series, Ginny & Georgia participated in a virtual reunion fundraiser for HD. The much-anticipated event raised nearly $5,000 and received more than 100,000 views on HDSA’s YouTube channel.

William H. Macy Hosts Virtual Bourbon Tasting Event to Support HDSA
On June 17th, stage and screen star William H. Macy hosted a virtual bourbon tasting event to support HDSA which raised more than $31,400!

Simi Fehoko Wears HDSA Cleats During the NFL’s #MyCauseMyCleats Campaign
Dallas Cowboy Simi Fehoko supported the fight against HD by wearing custom HDSA cleats during the NFL’s #MyCauseMyCleats Campaign during a game against the New Orleans Saints on December 2nd. Simi, who comes from an HD family, paid tribute to his grandmother who passed away from HD. This marks the second time an NFL player wore cleats to raise awareness of HD. Aaron Donald of the Los Angeles Rams participated in the initiative in 2018. Thank you Simi! And congrats for the win over the Saints!

HDSA Founder’s Day — September 18th
Each year, HDSA honors Marjorie Guthrie’s legacy to “do something” during the HDSA Founder’s Day campaign on September 18th. In 2021, the initiative raised more than $32,866 to ensure that our social workers, support groups, education programs and critical HD research continue to help improve the lives those affected by HD.

Athletes vs. HD
HDSA’s first Athletes vs. HD online auction in May generated a ton of awareness in the sports world and raised more than $2,600!
New York City Marathon Team Raises More Than $64,000

Eighteen runners from across the United States participated in the 50th Anniversary running of the TCS New York City Marathon and helped raise more than $64,000 to support the Huntington’s Disease Society of America.

“We can’t thank our runners enough for all their hard work to not only fundraise, but also for their willingness to take on the NYC Marathon to support the fight against Huntington’s disease,” said HDSA’s President and CEO Louise Vetter. “Each step they took through the five boroughs was a tribute to the strength of the HD community and helped to raise awareness for this devastating, rare brain disease.”

In addition to the generous donors supporting the HDSA runners, participation in the TCS New York City Marathon was made possible in part by sponsorship from Eisner Amper LLC.

Virtual Seventh Annual Freeze HD Raises More Than $212,000

On Saturday, October 16th, the stars came out to support the Huntington’s Disease Society of America at the Seventh Annual Freeze HD event. Hosted live from Los Angeles by Kate Miner, Scott Porter and Jason Ritter, more than $212,000 was raised to support HDSA’s mission to improve the lives of families affected by Huntington’s disease, a rare, inherited brain disease.

“Being virtual for the second straight year, allowed Freeze HD to share the story of HD families to a global audience while generating much-needed funds to support HDSA’s support programs,” said HDSA’s President and CEO Louise Vetter.

“It was a special night for HD families, and we are grateful to all who donated, sponsored, and performed and to our incredible hosts Kate, Scott and Jason for putting together an amazing show.”

To learn more about Freeze HD, please visit HDSA.org/freezehd.
Virtual 36th Annual HDSA Convention Welcomes Thousands from Around the World

Nearly 2,100 registrants from more than 33 countries participated in the Virtual 36th Annual HDSA Convention June 10th to 13th. The four-day virtual event featured world-class presentations on the latest in Huntington’s disease research and care. Despite not being able to meet in-person, the Virtual HDSA Convention allowed guests to connect virtually through the HDSA Convention app and visit the Virtual Exhibit Hall.

HDSA NATIONAL AWARDS

PERSON OF THE YEAR AWARD
Yvonne Sweeten

MARJORIE GUTHRIE AWARD
E.J. Garner

WOODY GUTHRIE AWARD
Doug Schulte

YOUTH/JHD AWARD
Jenna & Gia Mannone

CHAPTER OF THE YEAR AWARD
HDSA Illinois Chapter

AFFILIATE OF THE YEAR AWARD
HDSA San Francisco Bay Area Affiliate

Recorded sessions from the Virtual 36th Annual HDSA Convention are available at www.HDSA.org/convention.

Your HDSA Dollars at Work

BASED ON AUDITED FINANCIALS FOR THE FISCAL YEAR ENDED DECEMBER 31, 2021

Funds Allocation

- TOTAL 2021 REVENUE: $12.9 Million
- HDSA CENTER OF EXCELLENCE GRANTS: $1.55 Million
- RESEARCH GRANTS: $1.27 Million
- SOCIAL WORKERS: $587,000

Your HDSA Dollars at Work

Financials

Overview

- Program Services 78%
- Administrative Services 22%
- Research 24%
- Fundraising 16%
- Management 6%
- Education 8%
- Community Outreach 11%
- Family Services 35%
- Administrative Services

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### Statements of Financial Position

**AS OF DECEMBER 31, 2021 AND 2020**

<table>
<thead>
<tr>
<th>ASSETS</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$11,228,810</td>
<td>$9,339,030</td>
</tr>
<tr>
<td>Pledges and contributions receivable, net</td>
<td>2,598,770</td>
<td>1,133,748</td>
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<tr>
<td>Investments</td>
<td>2,503,034</td>
<td>2,310,097</td>
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<tr>
<td>Prepaid expenses and deposits</td>
<td>193,969</td>
<td>154,406</td>
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<tr>
<td>Property and equipment, net</td>
<td>28,993</td>
<td>35,148</td>
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<tr>
<td>Website costs, net</td>
<td>18,343</td>
<td>39,529</td>
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<tr>
<td><strong>Total Assets</strong></td>
<td><strong>16,571,919</strong></td>
<td><strong>13,011,958</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>LIABILITIES</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable and accrued expenses</td>
<td>120,126</td>
<td>214,836</td>
</tr>
<tr>
<td>Accrued compensation</td>
<td>263,269</td>
<td>294,228</td>
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<tr>
<td>Grants payable, net</td>
<td>1,364,174</td>
<td>1,283,055</td>
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<tr>
<td>Event revenue received in advance</td>
<td>61,177</td>
<td>17,800</td>
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<tr>
<td>Paycheck Protection Program loan payable</td>
<td>—</td>
<td>634,692</td>
</tr>
<tr>
<td>Deferred rent obligation</td>
<td>103,731</td>
<td>114,721</td>
</tr>
<tr>
<td>Obligation under capital leases</td>
<td>—</td>
<td>3,744</td>
</tr>
<tr>
<td><strong>Total Liabilities</strong></td>
<td><strong>1,912,477</strong></td>
<td><strong>2,563,066</strong></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>NET ASSETS</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Without donor restrictions</td>
<td>9,090,217</td>
<td>4,450,228</td>
</tr>
<tr>
<td>Board-operating reserve</td>
<td>1,806,203</td>
<td>1,805,969</td>
</tr>
<tr>
<td><strong>Total Liabilities And Net Assets</strong></td>
<td><strong>16,571,919</strong></td>
<td><strong>13,011,958</strong></td>
</tr>
</tbody>
</table>

**NOTE:** These Consolidated Statements reflect HDSA’s operations for the fiscal years as stated and include all affiliates. Please contact the HDSA National Office for a full copy of the audited financial statements.

### Consolidated Statements of Activities

**YEAR ENDED DECEMBER 31, 2021 WITH SUMMARIZED FINANCIAL INFORMATION FOR 2020**

<table>
<thead>
<tr>
<th>SUPPORT &amp; REVENUE</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public donations</td>
<td>6,095,983</td>
<td>3,116,252</td>
</tr>
<tr>
<td>Foundation grants and corporate contributions</td>
<td>2,330,828</td>
<td>3,115,452</td>
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<tr>
<td>Federated campaign</td>
<td>244,545</td>
<td>246,913</td>
</tr>
<tr>
<td>Special events (net of direct benefit to donors of $372,622 and $618,196 in 2020 and 2019, respectively)</td>
<td>3,361,360</td>
<td>2,254,487</td>
</tr>
<tr>
<td>Investment (losses) earnings, net</td>
<td>9,661</td>
<td>29,904</td>
</tr>
<tr>
<td>Donated services and materials</td>
<td>173,753</td>
<td>132,439</td>
</tr>
<tr>
<td>Gain on Paycheck Protection Program loan forgiveness</td>
<td>634,692</td>
<td>—</td>
</tr>
<tr>
<td><strong>Total Support and Revenue before net assets released from restrictions</strong></td>
<td><strong>12,938,478</strong></td>
<td><strong>8,970,625</strong></td>
</tr>
<tr>
<td><strong>Net assets released from restrictions</strong></td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td><strong>Total Support and Revenue</strong></td>
<td><strong>12,938,478</strong></td>
<td><strong>8,970,625</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EXPENSES</th>
<th>2021</th>
<th>2020</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program services:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>2,052,914</td>
<td>2,102,371</td>
</tr>
<tr>
<td>Family services</td>
<td>3,001,423</td>
<td>3,083,655</td>
</tr>
<tr>
<td>Education</td>
<td>704,533</td>
<td>761,319</td>
</tr>
<tr>
<td>Community outreach</td>
<td>—</td>
<td>1,023,900</td>
</tr>
<tr>
<td><strong>Total Expenses</strong></td>
<td><strong>8,727,528</strong></td>
<td><strong>8,781,595</strong></td>
</tr>
<tr>
<td><strong>Change in net assets</strong></td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td><strong>Net assets - beginning of year</strong></td>
<td><strong>10,448,892</strong></td>
<td><strong>10,259,854</strong></td>
</tr>
<tr>
<td><strong>Net Assets - End of Year</strong></td>
<td><strong>14,659,442</strong></td>
<td><strong>10,448,892</strong></td>
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Thank You HDSA Donors!

Thank You to Our Donors for Their Generous Support of HDSA With $1,000 or More
We are grateful for the gifts from the following estates who helped make our work possible in 2021.

Barbara L. Bell Trust
Estate of Charlotte F. Calhoun
Estate of Chauncey Perry Colwell, III
Terri Jakuboski Retirement Bequest
Estate of Charlotte A. Jordahl
The Carolyn L. Leetch Revocable Trust
The Lincoln National Life Insurance Company
Estate of Alice Ietje Livingston-Vail
Gregory A. Mattson Trust
Estate of James E. Patterson
Estate of June Rachman
The Donald Schlotz Living Trust
Joseph L.K. Snyder Trust
Symetra Life Insurance Company
Sylvia S Thomas Trust
United Life Insurance Company

Planned Giving

The Marjorie Guthrie Society

Until the day when scientists find a cure for HD, families across the country require access to the crucial research, care, education, and advocacy programs HDSA provides. The Marjorie Guthrie Society ensures that as we look to the future we’ll have the resources we need to continue providing help and hope to the HD community.

By including HDSA in your estate plans as the beneficiary of insurance, real estate, appreciated securities, or retirement plan you can create a legacy of giving that guarantees future generations will have the vital support they need to confront this devastating illness.

With the help of a financial planner, you can arrange your gift in a way that reduces your estate taxes and has the strongest possible impact on the lives of those affected by HD in the decades to come.

Join us in thanking the following individuals who have committed to support HDSA through their estate plans:
Anonymous (3)
Norman Baldwin
Nancy & David Clarke
Jerzy Gajewski
Catherine Hayes & Mark Wiesel
Dr. Barbara Heere
Amy Korber
Daniel & Katy Leonard
James Norris
Lachelle Parker
Mark Pinto
Gordon Sparks
Craig & Teresa Srajer

HDSA Leadership

Board of Trustees
Victor Sung, M.D.
Chair
Teresa Srajer
Chair-Elect
E.J. Garner
Past Chair
Kamran Alam
Treasurer
Jenne Coler-Dark
Secretary
Angela Allen
Dan Brennan
Jeff Carroll, Ph.D.
Mark Coe
Stacy Coen
Wendy Erler
Dr. Erin Furr-Stimming
Beth Hoffman, Ph.D.
Jay Hughes
Jonathan Klein, Esq.
Kelsey Porter
Dan Thomas
Leslie Thompson, Ph.D.
Vicki Wheelock, M.D.

Staff Leadership
Louise Vetter
President and Chief Executive Officer
Arik Johnson, PsyD
Chief Mission Officer
Rosemary Coluccio
Chief Operating Officer
Christopher Cosentino
Director of Marketing and Communications
Jamison Skala
Director of Development
HUNTINGTON’S DISEASE
SOCIETY OF AMERICA
505 Eighth Avenue
Suite 902
New York, NY 10018
(212) 242-1968
www.HDSA.org

HDSA’S FAMILY OF SERVICES
Get the help you need from the comfort and safety of your home at no cost.

- National Helpline: (800)-345-HDSA (4372)
- Online Support Groups: HDSA.org/osg
- Telehealth: HDSA.org/telehealth
- Disability Services: HDSA.org/disability
- Clinical Trial Participation: HDtrialfinder.org
- Locate Resources Near You: HDSA.org/locateresources

HIGHEST RATINGS
HDSA is an accredited non-profit with the highest ratings from the following national charity assessment organizations:

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